



Down Syndrome Caucus Hearing
February 26, 2009
Presented by Rich Robison,
Past President, National Down Syndrome Congress
On behalf of NDSS and NDSC

Good afternoon, my name is Richard Robison and I am the Past President of the National Down Syndrome Congress and the parent of Jason and Amy, my two adult children with Down syndrome. First, I would like to thank the Caucus for their commitment to people with Down syndrome and for giving us the opportunity to discuss issues that are important to all of us. We thank you for your advocacy for our children and look forward to continuing our work together.

I am delivering this testimony today to address the serious issues affecting my adult children, and the multiple barriers they and other adults with Down syndrome and other developmental disabilities face when they become adults and are no longer eligible to receive educational services.

Today, individuals with Down syndrome are active participants in the educational, professional, and social systems of our communities. There are more opportunities than ever before for individuals with Down syndrome to develop their abilities for

employment through educational experiences, live in the community independently and enjoy the benefits of living in our society.

Until Jason and Amy turned 21 years of age they were provided educational services under the Individuals with Disabilities Education Act known as IDEA.

However, on their 22nd birthdays, they were no longer eligible to receive educational services and those services came to an immediate end. In fact, in spite of the fact they were both eligible to receive Medicaid services, there was no law mandating provision of the supports they needed to live and work independently.

If the goal of our system is to create a society where people with disabilities are to capitalize on these opportunities, we must have safety net of federal support services to help them achieve their goals. We have a long way to go before our system meets the needs and provides the opportunities for people with disabilities to enjoy the privileges of belonging to an open society. There are still many challenges and issues still facing our community today. These barriers complicate every area of their lives – employment, transportation, housing, support services to enable them to carry out the activities of daily living – and their access to an inclusive community life.

Currently, Amy works part-time and Jason attends a day habilitation program. They both live at home. My wife and I provide the assistance they need to function day-to-day. As with all individuals with disabilities, the level of support they need ranges from

significant to occasional. To live on their own they would need assistance with meal planning, transportation, finances, personal care, participating in social and recreational activities, on the job assistance and many other activities – different levels of need for each, but assistance nonetheless.

For the past 100 years, the model of adult long term care in the United States has been in large congregate facilities. In more recent years, we have allowed individuals to move to smaller, community based facilities, but still institutionally based facilities. The cost of institutional care, in a large congregate setting of individuals with disabilities, in 2006 was \$123,000. I have had the opportunity to serve as a Protestant Chaplain in one of the oldest of these facilities in Massachusetts, The Fernald Developmental Center (now slated for closure). These settings, in my opinion, offer minimal opportunities to be included in work, recreational activities and enjoy the benefits of living and working among non-disabled peers.

There is a better alternative. Both Jason and Amy, because they are Medicaid eligible, are eligible for Medicaid Home and Community Based Services. This program allows states to waive the restrictive Medicaid rules which encourage segregation and non-work activity and provide support services in a more normal setting – in their community, in their own home, possibly with 1 or 2 roommates, have transportation and the in-home support services they need as well as assistance on a job – real work. The average cost for Home and Community Based Services in 2006 was \$39,000 a year. Compare that with the \$123,000 cost for a segregated life in a large congregate setting!

However, in 2006, there were over 280,000 individuals with disabilities on waiting lists for Home and Community Based Services in 31 states. Other states do not keep official waiting lists so the true number of individuals with unmet needs is much higher and growing with the aging of the U.S. population.

Massachusetts, my home state, maintain such a list for over 10 years until several years ago, self advocates and families filed a class action suit to obtain needed services, as they had been waiting for decades and their parent caregivers were aging. Once settled, the suit provided services for hundreds of needy individuals. After the class was resolved, the state stopped maintaining such a list and in fact raised the criteria for eligibility in order to reduce the number of potential applicants by nearly 50%.

Our educational system provides services and opportunities for individuals with Down syndrome through the Individuals with Disabilities Education Act (IDEA) for children from infancy to age 21 based on the premise of the Least Restrictive Environment and full integration into school and community life.

However, when our children turn 21 or 22, its like a switch is thrown and suddenly they are fighting for basic opportunities to be full participant citizens. My wife was forced to leave her full time career as a University researcher and go to work only part time at a much reduced salary, in order to provide necessary care and serve as our children's daily safety net and support.

We are asking for assistance to help prevent our children from graduating into a future which holds few opportunities for living independent, productive lives.

There are several ways in which the Congressional Down Syndrome Congress can help reconfigure programs so that individuals with Down syndrome can enjoy opportunities for a dignified productive life, opportunities which are available to non-disabled citizens.

- Urge the bi-partisan group of members of Congress who are currently developing a health care reform proposal to address provisions the Medicaid program dealing with long-term, community-based services under the Home and Community Based Services waiver program.
- Support legislation to improve the State plan amendment option by providing flexibility to states to provide the full range of services currently available under the Home and Community-Based Services waiver program.
- Support legislation such as the Financial Savings Account for Individuals with Disabilities that allows Medicaid beneficiaries to retain assets and enjoy the benefits of community living.
- Support Medicaid reform legislative efforts that focus on provisions that give consumer and family control of budgets and that enable individuals with disabilities to live truly independent lives of choice and control consistent with the principles of self-determination.

There is no easy fix to the current system for providing long term support services to people with Down syndrome to enable them to live and work in their communities.

However, we look forward to working with the member of the Congressional Down Syndrome Caucus to address these serious problems and make the system work more efficiently and effectively for the benefit of all Americans.

Thank you again for this opportunity.